DOCUMENT RESUME

ED 305 767 EC 212 566

AUTHOR	Agosta, John M.; And Others
TITLE	The Needs of Families: Results of a Statewide Survey in Massachusetts.
INSTITUTION	Human Services Research Inst., Cambridge, MA.
SPONS AGENCY	Massachusetts Association for Retarded Citizens, Newton.; Massachusetts State Dept. of Mental Health, Boston.
PUB DATE	Aug 86
NOTE	38p.; For related document, see EC 212 565. Some figures contain small print.
AVAILABLE FROM	Human Services Research Institute, 2336 Massachusetts Ave., Cambridge, MA 02140 ($6.00).
PUB TYPE	Reports - Research/Technical (143) -- Tests/Evaluation Instruments (160)
EDRS PRICE	MF01/PC02 Plus Postage.
DESCRIPTORS	Costs; *Delivery Systems; *Developmental Disabilities; Family Characteristics; *Family Environment; Family Programs; *Human Services; *Needs Assessment; Public Policy; Social Support Groups
IDENTIFIERS	*Massachusetts

ABSTRACT

The report presents findings from a survey of 243 caregiving families in Massachusetts which explored family needs and characteristics, as well as those of their developmentally disabled family members. Survey questions focused on family information, characteristics of the disabled family member, information on family needs, care-related costs incurred by families, information on external supports, and family placement preferences (in-home or out-of-home). Selected findings include the following: (1) the most frequently noted disabling condition, other than multiple disabilities, was Downs syndrome, followed by mental retardation; (2) families have multiple needs spanning several domains, including information, assistance in providing direct care, specialized services for the disabled family member, and networking; (3) families receive relatively few services to support their efforts; and (4) the greater the family's need for support, the more often they consider an out-of-home placement, although 66 percent of families noted no plans to seek such placement. Policy recommendations include the desirability of providing families with multiple service options and with timely and long-term support. Family support policy should be sensitive to a growing need for residential alternatives, especially as the person with disabilities reaches adulthood. The survey form is appended. (JW)

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The Needs of Families: Results of a Statewide Survey in Massachusetts

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THE NEEDS OF FAMILIES: RESULTS OF A STATEWIDE SURVEY IN MASSACHUSETTS

John Agosta, Alyse Bass and Rebecca Spence

(August, 1986)

The presence of a person with a developmental disability in the home can present the family with a variety of extraordinary challenges. Though problems related to the provision of care sometimes prompt parents to seek an out-of-home placement, most reject such placements in favor of continuing family care (Perlman, 1983). This care often is provided with little external support and with great difficulty. In response, several states have implemented programs to support family efforts (Agosta, Jennings & Bradley, 1985; Bates, 1985). The primary goals of these programs are: 1) to deter unnecessary out-of-home placement, 2) to enhance the caregiving capacity of families, and 3) to make it possible for families to choose to have their disabled member return home from an out-of-home placement.

Following the lead of these states, Massachusetts offers families limited forms of supports (i.e., principally respite care). Yet such services are inadequate in both their variety and capability to meet the current service demand. Moreover, there is increased interest in expanding the family's role in planning services both at the system and individual family levels. These conditions have prompted parents, advocates, and state officials to begin setting plans for establishing a more comprehensive and responsive system for supporting family efforts in the Commonwealth.

Note: This survey was sponsored by the Massachusetts Association for Retarded Citizens and the Massachusetts Department of Mental Health. The survey was primarily carried out by the Human Services Research Institute of Cambridge, Massachusetts.

Modification of the present system, however, must be predicated upon an understanding of the varying needs of caregiving families. In this light, the purpose of this paper is to present the findings of a recent survey of caregiving families in Massachusetts. Information is provided on the characteristics of families and their members with disabilities, and the various needs of these families. Moreover, factors related to identified needs and the placement preferences of families are examined.

Method

Approach Taken

Information was gathered from families across Massachusetts who have a member with a developmental disability living at home. The survey process was completed in three steps: 1) design of the survey form, 2) design of a sampling plan and distribution of the survey forms, and 3) compilation of the information collected.

Design of the survey form. The survey form was designed to reflect the preferences of families in Massachusetts and replicates an almost identical survey recently conducted by HSRI in the state of Virginia. Six basic areas of inquiry were identified and 45 questions were used to secure information related to the target areas or domains. (An appendix contains a copy of the survey form.) Several of these questions were based on a survey completed recently by Tausig (1985) in which he examined family characteristics and placement preferences in New York. Descriptions of the six domains and the types of questions included within each are as follows:

- family information: this section included seven questions concerning the characteristics of caregiving families (e.g., household composition, employment status of family members, family income, and sources of family income);

- information on the family member with a disability: this section included eight questions concerning the characteristics of the family member with a developmental disability (e.g., age, sex, disability type(s), and level of functioning);

- information on family needs: this section included 21 likert scaled items designed to check the level of family need in a variety of areas. Likert scales prompt respondents to make a judgement of the strength of their opinion on some issue (e.g., low to high agreement, little to great need). Scores on each item were summed to yield a "total family need" score;

- information on special costs to the family: this section included five questions. The first three concerned costs incurred by the family during the previous two years that were related to providing care (i.e., costs for adaptive equipment, home barrier removal, medical/dental services, and other extraordinary services). The fourth concerned costs for special items that were needed but not yet purchased. All dollar amounts noted by families were summed to yield a "total special costs score." The fifth question pertained to the "opportunity" costs incurred by families, such as the cost of not taking a job, turning down a promotion or transfer, or losing a job due to the demands of providing care;

- information on external supports: this section included three questions. The first two requested information on the services received by the family and then by its member with disabilities. The third requested that membership with any advocacy or self-help group be noted; and

- information on family placement preferences: this section included one question. Families were asked to note whether or not they had applied for, were planning to apply for, or were considering an out-of-home placement. In addition, families inclined toward an out-of-home placement were asked to specify their reasons.

Sampling plan and survey distribution. Crucial to any survey is its sampling plan. Ideally, the persons responding to a survey will, when considered together, be representative of the entire target population. In this study a purposive sampling approach was used. This method is characterized by the use of judgement and a deliberate effort to select sample members that are representative of the population. In this case, the target population was considered families throughout Massachusetts who provide home care to persons

with developmental disabilities of all ages and whose family member with disabilities receives either early intervention, public school, or adult day services. To select a suitable sample of this population, care was taken to balance the sample by the age of the family member with disabilities and by the contrasting population densities of the seven service districts in Massachusetts.

In all, 700 survey forms were allocated for distribution through 28 professionals involved with early intervention, public school and adult day programs. To assure a wide geographic distribution of survey forms, these persons were selected, in part, according to their area of residence.

The 28 "site coordinators" were each sent a letter thanking them for their help and advising them of the distribution process (e.g. directions for distributing survey forms across age groups), and a set number of prepared envelopes. The contents of these envelopes included: 1) a letter describing the project, 2) one survey form, and 3) a prestamped and addressed envelope for respondents to return completed questionnaires. Subsequently, the site coordinators mailed the packets to families known to be providing home care. Of the 700 survey forms, 379 survey forms were targeted for families of persons with disabilities aged 0-21 years, while 321 were alloted to families of adults over age 21. However, due to unforseen circumstances, 92 of these forms were not distributed by the site coordinators. The numbers of forms reaching families totaled 608, with 302 sent to families of persons 0-21 and 306 sent to families of persons over 21 years old. Figure 1 shows each of the participating distribution sites along with the number of survey forms distributed from each site.

Figure 1: Visual Display and Listing of Survey Sites

Service Region	Number of Forms Sent
1 -	76
2 -	84
3 -	143
4A -	55
4B -	105
5 -	86
6 -	69
TOTAL	608

Compilation of returned information. Each of the 608 forms was precoded to track return patterns and to simplify the data compilation process. The codes could not be used to identify individual families.

Returned questionnaires first were screened to assess whether the information could be used. Completed survey forms were removed from further consideration if: 1) the person for whom the form was completed did not have a developmental disability, 2) numerous questions were left unanswered or responses could not be understood, 3) the family no longer provided home care, or 4) the family surveyed was providing subsidized foster care to the person with disabilities. In all, only eight survey forms were eliminated from subsequent analyses. Following initial review, information on those forms considered valid was coded and prepared for statistical analysis.

Response Rate and Limitations

The number of families returning survey forms deemed acceptable totaled 243 of 608, a response rate of 40%. In comparison to similar studies undertaken elsewhere, a 40% response rate falls within expected norms. Figure 2 displays the pattern of survey forms by age group and region. Recall that the present sample only includes families whose member with a developmental disability is receiving some type of day program. The exact effects of this apparent sample bias were not examined. Moreover, mail surveys are vulnerable to error related to potential differences between those who choose to respond to the survey and those who do not. Consequently, survey findings may be biased in ways not readily observed and should be interpreted with caution.

Figure 2: Pattern of Returned Survey Forms

Age Group	Total Number Sent	Total Number Returned	Percent of Forms Returned
0-5 years	67	28	42%
6-21 years	235	91	39%
22 and older	306	122	40%

Results

The analysis was completed in two steps. First, rates of occurrence of various response options (i.e., frequency statistics) were compiled regarding each of the primary information areas defined earlier. Second, factors related to family needs and placement preferences were examined.

Frequency Statistics Regarding Six Primary Informational Areas

Information on Family Characteristics. Figures 3-6 presents summary information on the total sample regarding: 1) household composition, 2) employment status of family members, 3) presence of another person in the home with a disability, 4) total family income, and 5) sources of additional family financial support.

Selected Findings:

- The number of persons per household, excluding the family member with a disability, ranged from 1-7 and averaged 2.9;
- The percentage of families having a mother present totaled 93.8% (n=225), while the percent having a father present totaled 76.6% (n=183);
- The age of caregiving mothers ranged from 17-92 and averaged 49.3 years. In contrast, the age of caregiving fathers ranged from 19-82 and averaged 51.9;
- While 98 of the 243 families had no other children living at home, 36 had children at home aged 0-5 years, 28 had children aged 6-10, 29 had children aged 11-15, and 81 had childen at home aged 16 or over.
- The employment status of each household was examined by granting each person in a household two points for holding a full time job and one point for holding a part time job. Subsequently, points were summed for each household to yield a "total employment status" score. These scores ranged from 0-11, though 90% of the sample scored five or below. The average score averaged 2.52 per family.
- 18.5% of families (n=44) noted the presence of a person with a disability living at home other than the person for whom the questionnaire was completed.

- Regarding income, 58% of the families (n=124) noted a total family income of less than $30,000 per year. A sizeable percentage (15.3% or n=33) noted annual incomes of less than $10,000.

- 41% of families (n=94) noted sources of income other than paying jobs. The number of additional sources was summed for each family to yield a "total financial assistance score." These score ranged from 0-4 and averaged .52 per family.

Figure 3: Summary Statistics Regarding Household Characteristics

VARIABLE	# Of Families Responding	Range	Average	# Missing Cases
Total number in the household	243	1-7	2.90	0
Presence of a mother	243	YES=225	—	0
Mother's age	221	17-92	49.20	22
Presence of a father	243	YES=183	—	0
Father's Age	180	19-82	51.90	63
Total number of children	240	0-5	1.06	3
Children aged 0-5 years	239	0-3	0.19	4
Children aged 6-10 years	239	0-2	0.13	4
Children aged 11-15 years	239	0-3	0.16	4
Children aged 16 and under	239	0-5	1.06	4
Children aged over 16	239	0-5	0.58	4
Others in the household	240	0-7	0.15	3

Figure 4: Employment Status of Family Members

Family Member	Full Time	Part Time	Both	Not Employed	Number Missing
Mother	43	46	1	130	19
Father	122	9	1	48	63

Overall employment status per household was calculated by:

1) granting each person in the household two points for holding a full time job and one point for holding a part time job. and

2) summing points earned for each family.

Total Employment Status Scores: ranged from 0-11, and averaged 2.52/family.

Figure 5: Total Family Income

Income Category	Number of Families
$0 - $9,999	33
$10,000 - $19,999	33
$20,000 - $29,999	58
$30,000 - $39,999	34
$40,000 - $49,999	23
$50,000 or more	33
Missing Cases	29

Figure 6: Sources of Financial Assistance Other than Employment

Form of Assistance	Number of Families
NONE (no forms of financial assistance)	135
Other Forms	10
Aid for Dependent Children (AFDC)	8
Auxiliary Grant	1
Child Support/Alimony	9
Food Stamps	9
General Relief	2
Pension/ Rail Road or Veterans Benefits	13
Private Disability Insurance	1
Social Security	68
Unemployment Insurance	0
Missing Cases	14

Information on the person with disabilities. Figures 7-9 present summary information regarding the person's: 1) age, 2) sex, 3) disability type, 4) receipt of federal benefits (i.e., SSI, SSDI), 5) functioning level in five areas (mental development, physical development, behavioral competence, capacity to perform daily living skills, and need for special medical services), and 6) a "total functioning score" that represents the sum of responses to questions pertaining to functioning level.

Selected Findings:

- The age of family members with a disability ranged from under a year to 66 years and averaged 21.2 years. The number of persons aged 21 years and younger totaled 119, while the number overs 21 years was 124;
- 42.1% (n=102) of those living at home were female;
- The number of disabling conditions per person ranged from 1 to 5 and averaged 1.60. Over half (56%), however, had but one primary disability;
- The most often noted disabling condition, other than reporting multiple disabilities (n=92), was downs syndrome (n=67 or 28%), followed by mental retardation (n=44 or 18.4%). Though there is a high correlation between mental retardation and downs syndrome, respondents did not always view these disability labels as identical, choosing instead to distinguish between the two disability categories.;
- For persons aged 0 to 18 years, 28,3% (28 of 99 persons) received either SSI or SSDI or both. For persons aged over 18 years, 96.5% (136 of 141 persons) received either SSI or SSDI or both;
- The majority of persons with disabilities living at home (87.7% or n=192) exhibit no or occasional behavioral incompetence, while 11.2% of families (n=27) note moderate to extreme behavior problems; and
- "Total Functioning Level Scores" were calculated by summing five items pertaining to overall functioning (mental, behavioral, physical, medical, daily activities) that were scored from zero to three (a score of zero indicates little or no impairment, while higher scores indicate progressively greater impairment). Given a highest possible score of 15, "total functioning level" scores ranged from 1-14 and averaged 5.5 (higher scores reflect greater levels of disability).

Figure 7: Demographic Characteristics of Family Members with a Developmental Disability

AGE:

Range: Under a year to 66 years old
Average: 21.2 years
Unknown Age: 2 persons

SEX:

Number of Females: 42% (n=102 persons)
Number of Males: 58% (n=140 persons)
Unknown Sex: 1 person

PRIMARY DISABILITY TYPE:

Disability Type	Number of Persons
Don't know	5
Autism	3
Cerebral Palsy	14
Developmental Delay	11
Downs Syndrome	67
Emotional Disturbance	3
Epilepsy	1
Hearing Loss	0
Mental Retardation	44
Muscular Dystrophy	1
Physical Disability (other than listed)	3
Spina Bifida	1
Vision Loss	0
Other Disability Than Those Listed	4
Multiple	92
Unknown	4

Number of Persons with One Primary Disability: 136
Number of Persons with Multiple Disabilities: 92
Unknown: 15

Number of Disabilities per Person:
range: 1-5 disabilities
average: 1.60

Figure 8: Level of Functioning in Five Areas

Area	Level of Impairment: Little or No	Some	Moderate	Extreme	# Not Responding
Mental Development	15	33	122	48	25
Physical Development	71	60	59	28	25
Medical Impairment	95	77	55	14	2
Behavior Problems	106	86	22	5	24
Capacity for Performing Daily Living Skills	118	48	22	32	23

Total Functioning Level Scores: Scored from 0-15 with higher scores indicating a greater level of disability than lower scores)

ranged from: 0 to 14
averaged: 5.52
unknown: 29 persons

For children under 3 years old, responses to questions regarding mental and physical development, behavior problems, and capacity for performing daily living skills were not counted as valid. It was decided that accurate judgements regarding these areas are not easily made on children this young. The number of scores affected are reflected in the "# not responding" category and in the number for whom total function level scores could not be calculated.

Figure 9: Number of Persons Receiving SSI or SSDI By Two Age Groups

Federal Benefit	Age Group: 0 thru 18 (n= 99) No	Yes	Unknown	Over 18 (n=142) No	Yes	Unknown
SSI	72	27	0	21	120	1
SSDI	95	3	1	76	65	1
SSI OR SSDI	70	28	1	5	136	1
SSI AND SSDI	97	2	0	92	49	1

Information on family needs. Figure 10 presents summary information on the family's need for: 1) information, 2) assistance in providing direct care, 3) additional specialized services for the person with disabilities, and 4) social interaction. In addition, responses to 21 family need questions were summed to yield a "total needs score."

Based on the "t-test" statistic, Figure 11 displays a comparison of needs noted by families whose member with a disability is 21 years and under with families whose member with a disability is over 21 years. The "t-test" statistic is a numeric index used to judge the significance of the difference in responses between two samples. As the difference between the samples grows in magnitude (or reliability), the absolute value of the "t-test" statistic increases. In this case, the t-test statistic was used to compare responses given on the level of family needs by two sub-samples of the full survey sample.

Selected Findings:

- For many of the needs listed, significant numbers of familes noted "little or no need. However, this should not be taken to mean that families have little or no need for some services. Clearly, families reveal a wide array of needs, with some number of families noting an extreme need for each area listed;"

- The least noted needs were home barrier removal and special equipment (See Figure 10). The needs with the highest apparent magnitude concern information on where to obtain services and on future financial planning, and recreational opportunities for the family member with a disability. Review of family need scores, however, reveals significant variance in the type and level of family needs;

- Given 21 items and a highest possible score of 84, "Total Needs Scores" ranged from 0-76 and averaged 21.12 (the higher the score, the greater the need). These scores were computed by summing responses given for each of 21 likert scaled items. Each item was scored from zero to four. A score of zero indicates little or no need, while higher scores indicate progressively greater need;

Figure 10: Frequency Statistics Regarding Family Needs

	NO NEED 1	2	3	4	EXTREME NEED 5	# NOT RESPONDING
1. Information on the type of disability my disabled family member has	152	28	27	14	11	11
2. Information on how or where to get services	84	50	57	16	31	5
3. Information on how to best care for my disabled family member	120	45	37	14	17	10
4. Information on planning for the future financial welfare of my disabled family member.	58	25	51	37	69	3
5. Information on how to deal with behavior problems displayed by my disabled family member	109	32	36	18	17	31*
6. People who can come to my house and help me care for my disabled family member on short notice.	125	27	31	17	36	7
7. Qualified persons to care for my disabled family member overnight	115	23	42	23	37	3
8. Other families with a disabled child with whom I can talk to about raising my disabled. family member	147	42	24	10	11	9
9. A place where my disabled family member can go during the day while I do something else. like go to work, school or shop	159	13	24	15	25	7
10. Time to complete household chores or routines (shopping, house cleaning...)	163	16	20	14	20	10
11. More time just for myself	126	25	27	17	37	11
12. Specialized services for my disabled family member like speech or physical therapy	106	23	46	23	37	8
13. More opportunities for recreation for my disabled family member like bowling, swimming, dancing, or summer camp	75	24	52	21	43	28*
14. Money to use to care for my disabled family member	145	41	17	13	19	8
15. Temporary relief from caring for my disabled family member.	116	33	34	20	32	8
16. A way to transport my disabled family member around town when needed	178	26	11	2	18	8
17. Special equipment for my disabled family member (like arm or leg braces, a wheelchair, special shoes or toys)	202	11	6	7	9	8
18. Modifications to our house to make it easier for my disabled family member to get around. (like grab bars, ramp, wider doorways)	210	4	4	9	7	9
19. Medical insurance that covers more of the cost of medical care for my disabled family member	168	14	27	7	21	6
20. Doctors who understand how to care for my disabled family member.	147	21	31	15	24	5
21. Dentists who understand how to care for my disabled family member.	159	17	22	16	22	7

* Note: Responses provided by families with children in early intervention programs (n=28) were counted as missing.

- Families with disabled members aged 21 and under indicate a higher level of need on all scale items but two, the exceptions pertain to the need for recreational opportunities and transportation (See Figure 11); and

- Review of the level of need expressed by families in the two age related groups reveals statistically significant differences on 11 of the 21 items on the family needs scale (See Figure 11). These findings suggest that not only do families of younger persons have--on average--greater needs than those of older persons, but that there is a large and significant difference in the level of needs between the two groups.

Information on special costs. Figure 12 presents: 1) findings regarding the opportunity costs incurred by families, and 2) summaries of the special dollar costs incurred by families over the past two years,.

Selected Findings:

- 155 families (68.3%) noted no opportunity costs related to the provision of care, while 36 (16.4%) noted that a family member had to give up a paying job, 58 (26%) had not taken a job, and 25 (10.8%) had refused a job transfer or promotion;

- One third (n=79), however, report at least one type of opportunity cost. Additionally, when the opportunity costs noted by each family were summed to yield a "total opportunity cost" score, the scores ranged from 0-3 (highest possible score is three) and averaged 0.46 per family;

- Regarding special dollar costs, the majority of families note no extraordinary costs related to special equipment (84.7%), home barrier removal (92.1%), medical services (80.6%), or other special services (89.7%). It should be noted, however, that families may not know of the equipment or services available to them. Consequently, these findings may underestimate the special costs families would incur; and

- One third (n=79), however, note at least one type of special dollar cost. For these families, when special costs are summed across all cost categories, costs range from $20 to over $100,000 and averaged $4,984 per family (median equals $720).

Figure 11: Differences in Family Needs by Age Group

	21 AND UNDER (n=119) MEANS	OVER 21 (n=124) MEANS	t-TEST	# OF FAMILIES NOT INCLUDED IN CALCULATION
1. Information on the type of disability my disabled family member has	1.88	1.39	3.22**	2
2. Information on how or where to get services	2.63	2.07	3.16**	2
3. Information on how to best care for my disabled family member	2.18	1.64	3.30**	2
4. Information on planning for the future financial welfare of my disabled family member.	3.40	2.80	3.02**	2
5. Information on how to deal with behavior problems displayed by my disabled family member	1.86	1.75	3.61***	2
6. People who can come to my house and help me care for my disabled family member on short notice.	2.28	1.96	1.63	2
7. Qualified persons to care for my disabled family member overnight	2.40	2.20	1.05	2
8. Other families with a disabled child with whom I can talk to about raising my disabled. family member	2.00	1.26	5.28***	2
9. A place where my disabled family member can go during the day while I do something else. like go to work, school or shop	2.15	1.51	3.58***	2
10. Time to complete household chores or routines (shopping, house cleaning...)	2.09	1.29	4.86***	2
11. More time just for myself	2.41	1.76	3.58***	2
12. Specialized services for my disabled family member like speech or physical therapy	2.50	2.16	1.76	2
13. More opportunities for recreation for my disabled family member like bowling, swimming, dancing, or summer camp	2.35	2.39	-.19	2
14. Money to use to care for my disabled family member	1.99	1.49	3.08**	2
15. Temporary relief from caring for my disabled family member.	2.20	2.07	.71	2
16. A way to transport my disabled family member around town when needed	1.45	1.50	-.37	2
17. Special equipment for my disabled family member (like arm or leg braces, a wheelchair, special shoes or toys)	1.47	1.10	3.09**	2
18. Modifications to our house to make it easier for my disabled family member to get around. (like grab bars, ramp, wider doorways)	1.30	1.15	1.34	2
19. Medical insurance that covers more of the cost of medical care for my disabled family member	1.75	1.61	.85	2
20. Doctors who understand how to care for my disabled family member.	1.95	1.86	.49	2
21. Dentists who understand how to care for my disabled family member.	1.96	1.62	1.94	2

- Note: Responses provided by families with children in early intervention programs (n=28) were coded as missing.

- * $p < .05$
  ** $p < .01$
  *** $p < .001$

Figure 12: Special Costs Incurred by Families

OPPORTUNITY COSTS:

Type of Cost	Number of Families Noting an Occurrence	Percent of Families Noting an Occurence	# Not Responding
Given up a paying job	36	16%	24
Not taken a paying job	58	26%	20
Refused a job transfer or promotion	29	13%	29
At Least One of Above	72	32%	16

Instances of Opportunity Costs were summed per family to yield a Total Opportunity Cost Score.

Range: 0 to 3
Average: .46 per family

DOLLAR COSTS:

Type of Cost	Number Missing Cases	Number with Costs	Range	Average	Median
Special Equipment *	1	37	$20-11,000	$1,041	$400
Housing Modifications *	4	19	$20-35,000	$5,017	$500
Medical/Dent Services *	6	46	$90-60,000	$2,219	$500
Other Costs **	0	23	$66-99,999+	$11,133	$1,700

* Note: Costs incurred in the past two years.
** Note: Costs for items needed but not yet incurred.

Special Dollar Costs for families indicating some type of cost were summed to yield a Total Dollar Cost Score.

range of total dollar costs: $20 to $99,999
average total dollar costs: $4,984
median total dollar costs: $ 720

Information on services received. Figures 13 and 14 display service utilization patterns for services received by the person with disabilities and family members. In addition, Figure 15 summarizes the self-help or advocacy groups with which survey respondents hold memberships.

Selected Findings:

- Review of Figures 14 suggests that, on balance, families receive relatively few services to support their efforts;
- The most frequently offered family support service is respite, though the majority of families do not receive this service; and
- As shown by Figure 15, 40% (n=93) of those families surveyed do not belong to an advocacy or self help group. Of those that do, the most often noted membership is with the Association for Retarded Citizens (n=87 or 36.7%). Membership with multiple organizations and groups is noted second most often (n=33 or 13.5%).

Figure 13: Services Directed at the Family Member with a Disability By Age Group

	Age Group					
	0 thru 21 (total n=119)			over 21 (total n=124)		
Service	Yes	No	# Not Responding	Yes	No	# Not Responding
Early Intervention/Preschool	31	71	17	0	95	27
Special Education	92	23	4	14	83	25
Regular School	28	70	21	1	91	30
Sheltered Work Program	8	89	22	98	16	8
Physical Therapy	62	46	11	14	85	23
Speech or Hearing Therapy	73	37	9	26	69	27
Counseling	13	86	20	22	72	28
Recreation Program	40	63	16	41	59	22
Mobility Training	12	85	22	4	88	30
Other Services	11	61	47	11	61	50

Figure 14: Services Directed at the Family Caregiver By Age of the Family Member with a Disability

Service	Age Group: 0 thru 21 (total n=119) Yes	No	# Not Responding	Age Group: over 21 (total n=124) Yes	No	# Not Responding
Day Care	10	103	6	9	96	17
Homemaker Services	6	108	5	5	101	16
Companion Services	0	112	7	3	103	16
Family Counseling	18	94	7	22	90	10
Respite Services	52	64	3	38	75	9
Parent Training	4	107	8	5	100	17
In-Home Support	9	104	6	4	103	15
Behavioral Consultation	7	104	8	13	93	16
Parent Groups	23	89	7	6	100	16
Other Services	8	68	43	10	64	48

Figure 15: Membership with Advocacy or Self Help Groups

Organization	Number of Families
NONE -- No Memberships	93
Missing Cases	6
Association for Retarded Citizens	87
United Cerebral Palsy (UCPA)	2
Society for Autistic Children	1
Epilepsy Foundation Of America	0
Parent to Parent Support Group	2
Other Organizations	16
Multiple Organizations	33

Information on placement preferences. Figure 16 presents summary statistics related to the present placement preferences of families. In addition, for those families considering an out-of-home placement (n=82), Figure 16 also offers frequencies on the several reasons offered for such plans by two age groupings.

Figure 16: Family Placement Preferences

THE QUESTION:

Are you planning to request that your disabled family member be placed in a living arrangement outside your home in the near future (0-3 years)? (For example, to a foster or group home, state residential facility or institution) (CHECK ONLY ONE)

82 —
- 26 YES, our family has already applied for an out-of-home placement and we are waiting to hear about our status
- 16 YES, our family is planning to request an out-of-home placement
- 40 DON'T KNOW YET —our family is discussing this issue but we have not decided on what to do

155 NO, our family has no plans to seek an out-of-home placement

6 MISSING RESPONSES

REASONS GIVEN BY 82 FAMILIES:

	DD Persons Aged 0-21 (n=19)	DD Persons Aged over 21 (n=63)
disabled person wants to live somewhere else (eg., group home, own apartment)	3	17
disabled person could live away from home on his or her own	3	9
disabled person is old enough to live with others his/her own age	5	24
disabled person needs more care than the family can provide	6	9
disabled person has severe medical problems that cannot be met at home	1	1
disabled person has behavior problems that cannot be controlled	2	4
disabled person has special needs that the family is unable to afford	1	2
need to devote more time to other family members	3	9
disruption of family life	5	8
family has legal problems	0	2
death or illness of primary family caretaker	1	12
doctor or other professional(s) have advised placement	2	6
can't get needed services in the home	4	5
Other reasons	6	20

Selected Findings:

- Overall, the majority of families (n=161 or 66%) note no plans to seek an out-of-home placement. Of those 82 that do, 40 report that they are merely considering the option, 16 note that they plan to apply for placement, and 26 report that they already have. Additionally, it is worth noting that ALL families who wrote in the type of placement they were seeking noted a community placement of some type. No family indicated a preference for placement in a state institution;

- Of the 82 families who are at least considering an out-of-home placement, only 19 (23%) provide home care to persons aged 21 years and younger; and

- Reasons noted for an out-of-home placement vary by age of the family member with a disability. Generally, parents of older persons (older than 21 years) note reasons suggesting that the family member with disabilities is old enough to live away from the family home or that the family's capacity to provide care is diminished due to the death or illness of the primary caretaker. In contrast, parents of younger persons (0-21) note problems related to an inability to meet the habilitative needs of the person with disabilities and a need for relief from the provision of care.

Factors Related to Family Needs and Placement Preferences

Family situations are not static but evolve as family members age and pass from one life stage to the next (Konanc & Warren, 1984). This suggests that factors influencing family needs and placement preferences will vary with the age of the family member with disabilities and his or her caretakers.

Regarding home care, one key transition period is graduation from the public school system (around age 18-21). Consequently, following the lead of Tausig (1985), the sample was divided into two groups based on the age of the family member with disabilities: 1) persons aged 21 and under, and 2) persons aged over 21 years.

For each age group the identification of factors related to family needs and placement preferences was achieved by computing a correlation co-efficient between various selected study variables and each of the two dependent variables. A correlation co-efficient is a

numeric index that reflects the strength and direction of the relationship between two variables. The higher the absolute value of the co-efficient is, the greater the strength of the relationship. This tactic confirmed the importance of dividing the sample because it showed that the factors influencing family needs and placement preferences varied by age group.

Correlations with Family Needs. Figure 17 displays the correlations of selected variables with family needs by age group and shows that:

- Regardless of age group, the most telling factor associated with family need is the level of impairment of the family member with disabilities. The more severe the level of impairment is, the greater the family's need for support. The strength of the association, however, appears stronger in the 0-21 age group;

Figure 17: Correlations of Selected Variables with Total Family Need Scores By Two Age Groups

	AGE GROUP	
VARIABLE	DD Persons Aged 0 thru 21 (n=119) (SEE NOTE 1)	DD Persons Aged Over 21 (n=124) (SEE NOTE 1)
Total number in the household	-.024	.186 *
Mother in the family	.036	-.112
Mother's age	-.206	-.275 *
Father in the family	-.188 *	.045
Father's age	-.300 **	-.384 ***
Number of parents (one or two)	-.176	.075
Number children at home	-.078	.236 *
Children aged 0-16	-.050	.234 *
Children aged over 16 years	-.105	.157
Another at home with a disability	.119	.186 *
Household employment status	-.013	.163
Total family income	-.103	.166
Age of person with disability	-.175	-.014
Sex of person with disability	-.025	.114
Number of disabling conditions	.341 ***	.208 *
Level of mental impairment	.450 ***	.254 **
Level of physical impairment	.342 ***	.260 **
Level of medical impairment	.538 ***	.308 ***
Severity of behavior problem	.453 ***	.262 **
Ability to perform daily activity	.463 ***	.318 ***
Total Functioning Level Score	.635 ***	.420 ***
Special Dollar Costs	.124	-.210
Opportunity Costs	.456 ***	.206 *
Receipt of SSI or SSDI	.120	-.072
Number of Client Services Received	.214	-.084
Number of Family Services Received	.393 ***	.435 ***
Total Number of Services Received	.421 ***	.194
Membership in an Advocacy Group	.142	-.010

Note 1: * p < .05
** p < .01
*** p < .001

- Three other factors related to family needs regardless of age group include the father's age, opportunity costs and number of services received. As shown, the younger the father is, the greater the need for support. Also, the greater the number of opportunity costs or services received, the greater is the need for support; and

- Regarding the 21 and over group, various characteristics of the household are associated with family needs. Younger parents appear to have greater needs. Also, larger households or the presence of another at home with a disability is tied to family needs.

Correlations with Family Placement Preferences. Figure 18 displays the correlations of selected variables with family placement preferences by age group and shows that:

- The strength of relationships are generally low, especially with regard to the 21 and younger group. The anemic correlations pertaining to the younger group are in great part explained by the few families considering an out of home placement (n=19); there simply is not enough variance within this sub-group to identify specific factors related to placement preferences;

- Within the older group, the most telling factors related to placement preferences pertain to the need for various services (e.g., relief). The greater the family's need for support is, the more often they are considering an out-of-home placement. However, given findings presented earlier on the reasons for considering an out-of-home placement (see Figure 16), many families within this sub-group simply feel that the person with disabilities is old enough to leave home and begin his/her own life away from the family home.

Figure 18: Correlations of Selected Variables with Family Placement Preferences for Two Age Groups

VARIABLE	AGE GROUP: DD Persons Aged 0 thru 21 (n=119) (SEE NOTE 1)	AGE GROUP: DD Persons Aged Over 21 (n=124) (SEE NOTE 1)
Total number in the household	-.094	.065
Mother in the family	-.045	.053
Mother's age	.112	-.074
Father in the family	-.108	.161
Father's age	.030	-.014
Number of parents (one or two)	-.109	.217
Number children at home	-.109	.043
Children aged 0-16	-.106	.015
Children aged over 16 years	.069	-.021
Another at home with a disab	.170	.060
Household employment status	.081	.053
Total family income	.053	.225 *
Age of person with disability	.244 **	-.079
Sex of person with disability	.039	.005
Number of disabling conditions	.038	.176
Level of mental impairment	.270 **	.130
Presence of behavior problem	.129	.122
Total Functioning Level Score	.188	.087
Need temporary relief	.094	.415 ***
Need day care	.062	.099
Need recreational opportunities	.133	.279 **
Need Information (See Note 2)	.039	.246 **
Need Qualified Help (See Note 3)	.063	.314 ***
Need Trained Dentists	.061	.048
Need Trained Doctors	.184 *	.213 *
Total Need Score	.061	.335 ***
Special Dollar Costs	-.054	.172
Opportunity Costs	.165	-.063
Receipt of SSI or SSDI	.294 ***	.145
Number of Client Serv Received	-.128	.070
Number of Family Serv Received	-.098	.151
Total Number of Serv Received	-.280 *	.113
Membership in an Advocacy Group	-.030	.107

Note 1: * $p < .05$
** $p < .01$
*** $p < .001$

Note 2: "Need information" was calculated by summing 4 items in the total needs scale. These items pertain to: 1) how or where to get services, 2) how to care for the disabled person, 3) future financial planning, and 4) how to deal with problem behavior.

Note 3: "Need qualified help" was calculated by summing two items in the total needs scale. These items pertain to: 1) finding people to provide respite, and 2) finding qualified people to provide overnight respite.

Discussion

Research has long documented the habilitative needs of persons with developmental disabilities. Only recently have concerted efforts been made to examine the varying needs of families choosing to provide care at home. Regarding family needs, this study suggests that:

- There is a wide range of family needs. Survey results confirm that families can have multiple needs spanning several domains including information, assistance in providing direct care, specialized services for the person with disabilities, and social networking. Additionally, results show that families cannot be thought of in terms of an "aggregate average." Families function as unique caregiving units, sharing some needs but, having needs that are particular to the characteristics of the person with disabilities and the caregiving resources of the family;

- The level of disability greatly affects family needs. Regardless of age group, the severity of disability greatly effects the family's need for services. The more severe the disability, the greater is the need;

- The need for support is enduring. Survey results show that regardless of the age of the person with disabilities, families generally have a need for some type of support; and

- Family needs evolve as the family unit ages. Though the need for support is enduring, family needs are not static but evolve as the family unit passes from one life stage to the next. Study results suggest that:

    * In comparison to older families, younger families generally have a greater and more diverse need for support;

    * As family members age, there is an increased recognition that family care of all types ends eventually and that the same holds true for persons with disabilities. Many parents of persons with disabilities aged over 21 who are inclined toward an out-of-home placement reason that their disabled adult is old enough and often capabable enough to live away from the natural home.

Considered together, these observations suggest that policy designed to support families should:

- Provide families with multiple service options. Because no two persons with developmental disabilities or two families are alike, responsive family support programs must make available

to families a wide array of services and encouage each family to select those services that are most appropriate to its needs;

- Provide families with timely and long term support. The need for support services does not begin or end at some arbitrarily set date. Rather, support services must be available to families from the onset of disability to the time the person with disabilities leaves the natural home;

- Be especially responsive to the need of young families and families with extraordinary caregiving responsibilities. Establishing eligibility criteria is a perplexing issue that severely tests a society's capacity for equitably distributing scarce resources to those in need. Survey results, however, suggest that family support systems should be especially responsive to families of persons with disabilities aged under 21 and to families providing care to persons with severe levels of impairment or whose needs pose an extraordinary challenge to the family; and

- Work in tandem with policy designed to foster development of community based residential alternatives to the family. Because all family care ends eventually, family support policy should not be premised upon an expectation of continued home care. Rather, policy should be sensitive to a growing need for residential alternatives to the family, especially as the person with disabilities reaches adulthood.

Additionally, this study exemplifies the need for further examination of factors influencing the family's caregiving capacity and placement preferences. Though this study confirms previous findings regarding the diversity of family needs and the variables affecting placement (eg., Tausig, 1985), too little is known about how supports can be used to promote and enhance home care. Future research must eventually include analyses of existing family support systems for purposes of improving service delivery practices and spurring increased investment in family support.

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Perlman, R. (1983). Family home-based care: Critical issues for services and policies. New York, NY: The Haworth Press.

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APPENDIX A

MASSACHUSETTS FAMILY NEEDS SURVEY

INSTRUCTIONS

Thank you for helping us. Your cooperation will make it possible to improve services for persons with developmental disabilities in the Commonwealth of Massachusetts.

If you fill out this questionnaire by yourself, you can expect that it will take approximately 20-25 minutes to complete. However, some people would rather fill out this kind of questionnaire with a spouse or a relative or a friend helping them. This is fine, but may result in it taking a little longer to fill out. Regardless of how many people participate, please come to an agreement and mark only one answer.

Instructions are included throughout the questionnaire. We ask that you particularly note whether the instructions ask for a single answer or for all those that apply. We ask that you not indicate more than one answer when the instructions say "CHECK ONE" or "CIRCLE ONE."

You should remember that your answers will be kept strictly confidential. Should you come to a question you feel uncomfortable about answering, skip it. However, for us to get complete information, it is very important that you try to answer each question as accurately as you can.

When you have completed the questionnaire, remember to return it to us in the enclosed pre-addressed and pre-stamped envelope. PLEASE TRY TO SEND US YOUR COMPLETED QUESTIONNAIRE WITHIN THE NEXT TWO WEEKS!

THANK YOU

Today's date is: _____.

PLEASE TURN THE PAGE

Send Completed Questionnaire to:

Massachusetts Association for Retarded Citizens
c/o Alyse Bass, Survey Coordinator
217 South Street
Waltham, MA 02154

SURVEY OF FAMILIES WHO HAVE A MEMBER
WITH A DEVELOPMENTAL DISABILITY

No: _____
Sample: ___

PART I: FAMILY INFORMATION

1. What is your relationship to your family member with a disability? (CHECK ONLY ONE)

__ natural parent
__ adoptive parent
__ foster parent
__ step parent
__ other -specify: _____

2. What is your mailing address zip code? _____

3. Please list ALL FAMILY MEMBERS living in your house, their AGES, and whether or not they are EMPLOYED.

DO NOT COUNT YOUR FAMILY MEMBER WITH A DISABILITY IN THIS LIST BUT REMEMBER TO INCLUDE YOURSELF. Please only write down the family member's relationship to the disabled person (mother, father, aunt, brother, grandmother, etc.) NO NAMES PLEASE

RELATIONSHIP	AGE	EMPLOYMENT STATUS			
		Homemaker	Employed Full Time	Employed Part Time	Not Employed
1.					
2.					
3.					
4.					
5.					
6.					
7.					
8.					
9.					
10.					

4. Other than your family member with a disability (for whom you are completing this questionnaire), are their any other persons living in your household who have significant health or emotional problems? (CHECK ONE ONLY)

___ YES ___ NO

5. What was the TOTAL taxable income last year (1985) of primary wage earners in your household? (CHECK ONE ONLY)

__ $0 - $9,999
__ $10,000 - $19,999
__ $20,000 - $29,999
__ $30,000 - $39,999
__ $40,000 - $49,999
__ $50,000 or more

6. Does your FAMILY MEMBER with a disability receive any of the following government benefits? (CHECK ALL THAT APPLY)

__ NONE (none of the government benefits listed below are received)

__ Supplemental Security Income (SSI)
__ Social Security Disability Insurance (SSDI)
__ Medicaid
__ Medicare

7. Does your family household receive any of the following forms of financial assistance? (CHECK ALL THAT APPLY)

__ NONE (no forms of financial assistance are received)

__ Aid for Dependent Children (AFDC)
__ Food Stamps
__ General Relief
__ Pension/ Rail Road or Veterans Benefits
__ Private Disability Insurance
__ Unemployment Insurance
__ Child Support/Alimony
__ Auxiliary Grant
__ Social Security
__ Other_____
_____
_____

PART II: INFORMATION ON YOUR FAMILY MEMBER WITH A DISABILITY

8. How old is your family member with a disability? ___years ____months

9. What sex is your family member with a disability? __ Male __ Female

10. What disability best describes the condition your family member with a disability has? (CHECK ALL THAT APPLY)

__ Don't know

__ Autism
__ Developmental Delay
__ Cerebral Palsy
__ Emotional Disturbance
__ Epilepsy
__ Hearing Loss
__ Mental Retardation
__ Downs Syndrome
__ Muscular Dystrophy
__ Spina Bifida
__ Vision Loss
__ Physical Disability other than those listed--specify: _____
_____
__ Other --specify: _____
_____

11. To what extent has your family member's disability affected his or her MENTAL or INTELLECTUAL DEVELOPMENT (i.e., the capacity to learn new things and apply past learned skills as needed)? (CHECK ONE)

__ Not at all
__ Mildly
__ Moderately
__ Severely

12. To what extent has your family member's disability affected his or her PHYSICAL development (i.e., ability to move around or do things without the physical assistance of others)? (CHECK ONE)

__ Not at all
__ Mildly
__ Moderately
__ Severely

13. To what extent does your disabled family member require SPECIALIZED MEDICAL ATTENTION (i.e., from doctors or nurses to monitor health status or provide specialized health care)? (CHECK ONE)

__ No Need
__ Some Need
__ Moderate Need
__ Extreme Need

14. How often does your disabled family member behave in ways that pose a considerable problem for you or other family members (e.g., has excessive tantrums, breaks things, hits others, hurts himself or herself, eats unhealthy things)? (CHECK ONE)

__ Never
__ Sometimes (occasionally)
__ Regularly
__ Very frequently

15. How much assistance does your disabled family member need to perform every day activities like eating, dressing, bathing, toileting, and toothbrushing?

__ Very Little
__ A Moderate Amount
__ Frequent
__ Almost Constant

PART III INFORMATION ON FAMILY NEEDS

Below is a list of needs some families have in caring for their family member with a disability. Please rate from 1-5 YOUR family's PRESENT level of need by CIRCLING THE APPROPRIATE NUMBER. The lower the number you circle, the less need your family has. The higher the number you circle, the greater your family's need.

For example, if your family presently has NO NEED of "information on where to get special services," circle the number 1. If your family has an EXTREME NEED for that type of information, circle the number 5. If your level of need is somewhere in between, circle the number that best describes your family's overall present level of need. (CIRCLE ONLY ONE NUMBER PER STATEMENT)

	NO NEED				EXTREME NEED
16. Information on the type of disability my disabled family member has	1	2	3	4	5
17. Information on how or where to get services . . .	1	2	3	4	5
18. Information on how to best care for my disabled family member	1	2	3	4	5
19. Information on planning for the future financial welfare of my disabled family member.	1	2	3	4	5
20. Information on how to deal with behavior problems displayed by my disabled family member	1	2	3	4	5

	NO NEED				EXTREME NEED
21. People who can come to my house and help me care for my disabled family member on short notice. .	1	2	3	4	5
22. Qualified persons to care for my disabled family member overnight	1	2	3	4	5
23. Other families with a disabled child with whom I can talk to about raising my disabled. . . . . family member	1	2	3	4	5
24. A place where my disabled family member can go during the day while I do something else. . . like go to work, school or shop	1	2	3	4	5
25. Time to complete household chores or routines (shopping, house cleaning...)	1	2	3	4	5
26. More time just for myself	1	2	3	4	5
27. Specialized services for my disabled family member like speech or physical therapy	1	2	3	4	5
28. More opportunities for recreation for my disabled family member like bowling, ... swimming, dancing, or summer camp	1	2	3	4	5
29. Money to use to care for my disabled family member	1	2	3	4	5
30. Temporary relief from caring for my disabled family member.	1	2	3	4	5
31. A way to transport my disabled family member around town when needed	1	2	3	4	5
32. Special equipment for my disabled family member (like arm or leg braces, a wheelchair, . . special shoes or toys)	1	2	3	4	5
33. Modifications to our house to make it easier for my disabled family member to get around. . . (like grab bars, ramp, wider doorways)	1	2	3	4	5
34. Medical insurance that covers more of the cost of medical care for my disabled family member . .	1	2	3	4	5
35. Doctors who understand how to care for my disabled family member.	1	2	3	4	5
36. Dentists who understand how to care for my disabled family member.	1	2	3	4	5

PART IV: SPECIAL COSTS

Many families have extraordinary expenses related to providing care to their family member with a developmental disability. These next few questions request information on some of the costs your family may have had.

37. **IN THE PAST TWO YEARS**, have you bought any special items or devices for your family member with a disability? (Examples include leg or arm braces, wheelchairs, special chairs, specially designed toys, respirator, monitoring devices, and other specially designed devices)

__ YES __ NO

If you checked YES, please estimate the TOTAL COST THAT YOU PAID for these items. (Remember only to count costs you had to pay in the past two years)

Total Cost: $ _____.

38. **IN THE PAST TWO YEARS**, have you paid for special modifications to your house to make it easier for your family member with a disability to get around or for you to provide care? (Examples include installation of grab bars in the bathroom, widening doorways, building a ramp or other special home alterations)

__ YES __ NO

If you checked YES, please estimate the TOTAL COST THAT YOU PAID for these alterations. (Remember only to count costs you had to pay in the past two years)

Total Cost: $ _____.

39. **IN THE PAST TWO YEARS**, have you paid for specialized medical or dental services for your family member with disabilities? (Examples include surgery, hospitalization or repeated office calls

__ YES __ NO

If you checked YES, please estimate the TOTAL COST THAT YOU PAID for these services. (Remember only to count costs you had to pay in the past two years)

Total Cost: $ _____.

40. Please specify below any special devices or services related to the care of your family member with a disability that are needed but that you just cannot afford at this time.

Other Special Services or Devices	Approximate Cost
a.	
b.	
c.	
d.	
e.	

41. To meet the needs of your family member with a disability, has anyone in your household: (CHECK ONE OPTION PER QUESTION)

    a. given up a paying job? __ YES __ NO

    b. not pursued paid employment? __ YES __ NO

    c. refused a job transfer or promotion? __ YES __ NO

PART V SERVICES RECEIVED NOW

42. Please specify below which of the services listed are PRESENTLY received BY YOUR FAMILY to help you provide care to your family member with a disability. If you do not receive a specific service place a CHECK in the column marked "NO." If you do receive the service, place a check in the column marked "YES."

    In addition, for those services received, specify the party (or parties) who pay for the service. (CHECK ALL SOURCES OF PAYMENT THAT APPLY)

SERVICE	Service Received? NO	YES	PAYMENT SOURCE: Dept of Social Services	Dept of Mental Health	Dept of Public Health	Public Schools	Family Pays Cost	Other Sources	Don't Know
Day Care									
Homemaker (home health aide)									
Companion Services									
Counseling									
Respite Care or Sitter Service									
Training in Parenting Skills									
In Home Support Services									
Behavior Consultation									
Parent Support Groups									
Other:									
_____									
_____									

43. Please specify below which of the listed services are PRESENTLY received BY YOUR family member WITH A DISABILITY. If she or he does not receive a specific service place a CHECK in the column marked "NO." If s/he does receive the service, place a check in the column marked "YES."

    In addition, for those services received, specify the party (or parties) who pay for the service. (CHECK ALL SOURCES OF PAYMENT THAT APPLY)

SERVICE	Service Received? NO	YES	PAYMENT SOURCE: Dept of Social Services	Dept of Mental Health	Dept of Public Health	Public Schools	Family Pays Cost	Other Sources	Don't Know
Early Intervention/Preschool									
Special Education									
Regular School									
Sheltered Work Program									
Physical Therapy									
Speech or Hearing Therapy									
Counseling									
Recreation Program									
Mobility Training									
Other:									
_____									
_____									

44. Please specify which advocacy or self help organizations any members of your family belong to: (CHECK ALL THAT APPLY)

__ NONE

__ Association for Retarded Citizens (ARC)
__ United Cerebral Palsy (UCPA)
__ Society for Autistic Children
__ Epilepsy Foundation of America
__ Parent to Parent network group
__ Other -Specify: _____
_____
_____

PART VI PLACEMENT PLANS

45. Are you planning to request that your disabled family member be placed in a living arrangement outside your home in the near future (0-3 years)? (For example, to a foster or group home, state residential facility or institution) (CHECK ONLY ONE)

__ YES, our family has already applied for an out-of-home placement and we are waiting to hear about our status

__ YES, our family is planning to request an out-of-home placement

__ DON'T KNOW YET —our family is discussing this issue but we have not decided on what to do

__ NO, our family has no plans to seek an out-of-home placement

If you checked YES or DON'T KNOW YET, please specify why you have requested or may request an out-of-home placement (CHECK ALL THAT APPLY)

__ disabled person wants to live somewhere else (eg., group home, own apartment)
__ disabled person could live away from home on his or her own
__ disabled person is old enough to live with others his/her own age
__ disabled person needs more care than the family can provide
__ disabled person has severe medical problems that cannot be met at home
__ disabled person has behavior problems that cannot be controlled
__ disabled person has special needs that the family is unable to afford
__ need to devote more time to other family members
__ disruption of family life
__ family has legal problems
__ death or illness of primary family caretaker
__ doctor or other professional(s) have advised placement
__ can't get needed services in the home
__ Other -Specify: _____
_____
_____

THANK YOU FOR COMPLETING THIS QUESTIONNAIRE.
PLEASE CHECK TO SEE THAT YOU HAVE ANSWERED ALL THE QUESTIONS.
DON'T FORGET TO MAIL IT BACK TO US !! THANK YOU!